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Mr. Fernand Belisle,
Secretary General,
CRTC,
1 Promenade du Portage,
Terrasses de la Chaudiere,
Hull, Quebec.

12 March 1990

Dear Mr. Belisle,

I wish to complain vehemently about a recent experience with a "Morningside" producer, and with an item produced 13 February 1990 and aired at 10:32 am on the CBC am radio network. Perhaps you could obtain a copy of this half-hour item for reference, as it demonstrates well a continuing problem at CBC with respect to the effect much of CBC Network coverage on members of a disabled group.

The item purported to be about environmental hypersensitivity, which is an umbrella term referring to what most authorities have described as a "compendium of disorders" having in common a sometimes disabling reaction or vulnerability to natural and synthetic chemicals at levels of exposure not apparently affecting others.

The "Morningside" problem occurred, in my opinion, due to arrogance on the part of the producer and executive producer of the show, who refused to listen to information that should have led them to approach the subject material in a less confusing and harmful way, something a related Ontario provincial commission recommended to the media nearly five years ago.

This complaint involves

- inaccurate and damaging information,
- the omission of material critical to the interests of the people affected,
- the denial of an opportunity to respond,
- unprofessional conduct on the part of the producer and executive producer, and
- the failure of CBC management to deal responsibly with continuing complaints about coverage of this subject (and about the same producer).

The complaint is made in a spirit fully supportive of the constructive and dynamic discussion normally associated with media coverage of an issue, with a full appreciation of our pluralistic society and of the responsibility journalists cherish of including differing points of view. I am not writing to

complain simply that the program participants had different views than my own.

History:

1. Environmental sensitivities are not one illness. (There are not "two sides".)
2. Total Allergy Syndrome is not an appropriate term. Most medical authorities would state that the various problems experienced by people with sensitivities can not be explained simply in terms of immune system dysfunction, but may involve any system of the body.
3. Twentieth Century Disease is also a misnomer. ES is not new. Environmental sensitivities have been around for generations. My grandfather and several of my aunts and uncles had (have) them, as did (do) the ancestors (and relatives) of thousands of Canadians diagnosed with various forms of these problems.
4. A bibliography "Healthy Environments for Canadians", published by Health and Welfare, lists articles in medical literature dating back to 1908.

The illnesses:

5. Although the "Morningside" piece equated the ideas of clinical ecologists with the illness itself, most people with sensitivities do not go to clinical ecologists for treatment. While the ecologists have helped some patients, clinical ecology and environmental sensitivity are not synonymous. The ecologists concentrate on immune system dysfunction, but allergists have quite correctly pointed out, on many occasions, that many patients with sensitivities do not exhibit immune system dysfunction.

The liver and endocrine systems are implicated in some cases. Sometimes the problem seems to relate to digestive enzymes. Sometimes sensitivities result from fungal or other toxicity. It is inaccurate to say the problems are caused by foods and the environment; sometimes the illnesses cause people to be vulnerable to substances they are sensitive to.

The controversy in the medical community is not about whether or not some people are sensitive to chemicals, and suffering disabling effects. The controversy is about diagnostic and treatment protocols proposed by clinical ecologists. Many medical institutions and self-help groups have called for more research, including the AEHA, AGES, PES, CMA, OMA, Ontario MoH, and HWC.

6. Meanwhile, several authorities, including the OMA, two provincial commissions, and the Chief Coroner of the Province of Ontario, have called for action on the social concerns of people affected, while medical science explores the various etiologies, diagnoses, and treatments.

7. As is the case with most concerns, in most professional groups, debate on the subject has ranged from a reasonable and reasoned expression of theories, science, and professional concerns, to irresponsible comments which have, in at least one instance, contributed to the suicide of a person affected. Unconstructive bickering amongst doctors led the Thomson commission (Ontario, 1985) to devote a whole section of their report to "The Professional Debate", where Judge Thomson and his panel of government and OMA appointed doctors reported:

"confidence in the health care system is eroded when productive dialogue between different medical specialties disappears, or is replaced by acrimonious debate."

and

"Protagonists take up positions that are **clearly untenable**, such as...'all medical treatments are based on sound scientific research'".

Attention:
Mr. Fernand
Belisle
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Media coverage:

8. The same committee made special mention of how the media has helped polarize debate, stating: "Our unease has been...fueled by media reports that highlight extreme positions".

9. CBC's coverage has been variable in quality over the years, from helping to ruin the reputation of one person in Smiths Falls who has ES, (contributing to misconceptions and unfavourable attitudes in the Ottawa area that led to at least one suicide) to producing network specials which "highlight extreme positions" and inappropriately equate sensitivities with allergies.

CBC coverage tends to ignore the ocean of acceptance and concentrate on a puddle of controversy, breeding confusion even after responsible authorities have validated the concern. (As mentioned above, there is legitimate controversy about the sometimes less than comprehensive approach of some clinical ecologists.)

"Morningside":

Despite repeated approaches their show and to management, "Morningside" seems still unaware of how their approach to this story is both unfair and harmful; how it violates not only common sense, policies, and ethics, but also persons with this disability.

10. Because the host of "Morningside" seems so reasonable to most Canadians, the broadcast of misleading information and the denial of the right to answer is of more concern than it might be in another venue. CBC's Program Policies • **STATE THAT ITS** special role as a national public Corporation dictates that it should preserve "the democratic values of our society", "it carries a unique responsibility", and "it cannot be like the others".

11. Some of the CBC policy guidelines broken include:

"research should be carried out in cooperation with responsible research agencies"

"exercise care not to be 'captured' by the viewpoint of those who may have special interests"

"The statement of fact must contain all the relevant facts and not omit certain facts which if included would change the whole complexion"

Freedom of speech includes the right to respond.

12. The interview was billed as being about "environmental hypersensitivity". It was not. It was really about the pros and cons of clinical ecology approaches.

13. The "Morningside" program equated environmental sensitivity with the theories of clinical ecologists. As mentioned above, only some people with sensitivities see clinical ecologists. Terry Macleod, the "Morningside" producer, and Ms Pehleman (sp?), the executive producer, refused to listen to or allow to be included concerns about how, because of this, playing clinical ecologists against members of other specialties is an inappropriate way to approach our story.

The doctors represented "special interests" rather than responsible research. There has been a long (and substantially irrelevant) debate between ecologists (such as guests John Molot, M.D., and John Gerrard, M.D.) and allergists (such as Dr. David McCourtie, the other guest from the medical profession). These parties are bit part players representing special interests in the issue, who concentrate on elements of the problem relating to immune system dysfunction, when most people with the problem experience symptoms involving other systems of the body, and many do not exhibit immune system dysfunction.

14. Because these parties are locked in a debate about elements of the problem relating to the immune system, and techniques and theoretical explanations also concerning the same system, their adversarial positions do not reflect debate on this subject in the community as a whole. In fact, this misrepresentation of discussion on this issue is perhaps the biggest obstacle to understanding what's going on, and to exploring the legitimate and useful discussion recommended by and Ontario provincial commission in 1985. Former Provincial Court Judge George Thomson and his panel of doctors ~~have~~ the needs of a "growing number of patients". **MADE SEVERAL RECOMMENDATIONS FOR ACTION ON**

15. The only consumer taking part in the discussion explained her experience strictly through a recitation of clinical ecology theory. She did not represent the broad experience of members of this disabled group, and could not speak accurately to the broader concerns of people with these problems. Many other possible descriptions exist to augment the clinical ecologists approach, which has been repeatedly described as unsubstantiated and incomplete, not only by other doctors, but by many members of this disabled group.

16. In effect, ownership of the concerns of a heterogeneous consumer group was stolen from us, and given to doctors who represent only one small window onto the problem. Then that small (special interest) group was presented as representing the problem as a whole. The fact that most people with these problems do not see ecologists for treatment and that many of us are very concerned about the way the ecologists present our case was not mentioned; in fact the possibility was both forbidden and ridiculed in conversations with the producer lining up the item, and in conversations with him last fall.

17. The rather large and legitimate movement in the disabled community, the "demedicalization of disability", was unknown to and apparently beyond the comprehension of the producer lining up the item. Disabled persons with many different

problems are tired of journalists and others going to doctors in various specialties (who have their on axes to grind) instead of talking with the group directly. Mr. Macleod seems unable to accept that disabled persons can speak for themselves, separate and distinct from reciting the ideas of one group of doctors, and that we might, as consumers, have valid concerns about the fact that our views are ignored or misrepresented (various investigations have identified this); had been encountered last fall. Despite several complaints to management, apparently nothing was done to make him more aware of offensiveness and potential damaging effects of his approach. Such incredible arrogance!

HIS
ATTITUDE
PROBLEM

18. While the bit part doctors in the piece were concentrating on making points against each other's theories and techniques on the subject, a substantial body of consensus and legitimacy amongst much more significant parties was given only passing mention.

Several of the guests referred to "allergies", when a person can not have allergies to substances other than proteins, and in a social context where the debate over whether the problem should be referred to as allergy has been sorted out by more responsible authorities than those on the show.

At one point a doctor mentioned the other doctor's approach was not funded by OHIP, giving the impression the concern is not paid for by medicare. In fact, OHIP pays part of the costs of sending people outside Canada for treatment.

19. At one point the question is summed up as being "are these patients being made sick by foods and the environment". In fact, the illnesses, in some cases, may leave a person vulnerable to the effects of toxins produced in the body or coming in from outside, or to foods, and so on. The sensitivity may be a symptom of some system of the body not functioning "properly", rather than a result of the exposure itself. In other words, it may not be the "environment that is making people sick", but that their susceptibility to the environment may have some other cause.

20. The Ottawa-Carleton Regional District Health Council, the only health organization mentioned as recognizing the problem, is perhaps the least significant of hundreds of organizations in the world who do recognize the problem. A

well intentioned but poorly informed host damns by faint praise.

An additional facts that might have changed the "whole complexion":

Environmental sensitivities are recognized as disabling by:

The United Nations Decade of Disabled Persons
 The World Health Organization
 British Medicare
 NASA
 Health and Welfare
 Environment Canada
 Federal Secretariat for Disabled Persons
 Consumer and Corporate Affairs
 Canadian Human Rights Commission
 Communications Canada
 Treasury Board
 Public Service Commission
 Secretary of State for External Affairs
 Finance Canada
 National Capital Commission
 Revenue Canada
 Majority Leader's Office, Canadian Senate
 All three federal political parties
 Statistics Canada
 Supply and Services
 Parliamentary Standing Committee on Health and Welfare
 Chairman, Parliamentary Standing Committee on Disabled and Human Rights
 Canada Mortgage and Housing Corporation

Ontario:
 Premier's Office
 Health Ministry
 Coroner's Office
 Office for Disabled Persons
 Ministry of the Environment
 Ministry of Education
 Attorney General's Office
 Ministry of Community and Social Services
 Ministry of Housing
 Ontario Human Rights Commission
 Ministry of Labour
 Ombudsman's Office
 Worker's Compensation Board
 All three provincial parties
 Ontario Chief Coroner

Ottawa-Carleton
 Regional Municipality

Health department
 Social Services Department
 Chairman's office
 Health committee of council

Ottawa Board of Education
 Carleton Board of Education
 Carleton University Disabled Co-ordinator
 University of Ottawa Disabled Persons Coordinator

Several Ottawa area Hospitals have opened discussion on how to provide reasonable accommodation to members of this disabled group.

Due to the arrogance and bigotry of the producer organizing the segment, the "Morningside" item was very much like the following analogy.

Suppose "Morningside" did a story about "being black", long after international, national, provincial, and local authorities had decided, through studies, commissions, and acts, that black persons were legitimate and had many issues unrelated to the colour of their skin. Suppose "Morningside" were to interview ~~three~~ three anthropologists discussing the issue through a discussion of a scientifically questionable school of thought without allowing comment from black activists on the subject of how approaching the issue from this perspective had previously contributed to damages, (and in our case, disabilities, disenfranchisement, and deaths).

The parallel is precise. The producer and executive producer even denied an opportunity to express other perspectives which have been key to getting out from under the poorly developed **theory** of the ecologists. In fact, as the primary activist on this subject in Canada, I would say it has only been by escaping the very framing of the discussion put forward by "Morningside" which has resulted in the gains listed above.

Considering their tremendous influence, only once CBC network journalists understand that their approach is contributing to damaging attitudes that we can expect to be able to begin to undo damaging attitudes some CBC journalists have fostered irresponsibly. "Morningside" did it in this case by denying the idea that disabled persons can speak for themselves, that perhaps we have a better handle on our situation than those in the medical community who place their own concerns about theory, description, and who gets paid for what ahead of the reality we experience daily.

I hope can act on this complaint, and encourage a less bigoted attitude on this subject in the dark corners of the Corporation. Perhaps you could encourage CBC management to deal with their corporate responsibility to ensure CBC journalists follow policy, don't disenfranchise broader perspectives of consumers by describing their needs only in the language and theory of a limited cross section of service providers, in the process denying any opportunity to express a differing view.

As an aside to CBC, I would mention that only 10 per cent of the concerns of people with environmental sensitivities relate to medicine. So far network producers at the Corporation, unlike other authorities, have ignored the other 90 percent of our concerns. This seems to be because the Corporation is only capable of seeing us through the eyes of doctors who are "responsible authorities" who know better what needs to be said about our situation than we do ourselves.

The arrogance is astounding. Damages from the problematic attitudes fostered by journalists in various venues continue to mount.

Sincerely,



Chris Brown
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cc "Morningside"
Bill Morgan, CBC Ombudsman
John Dwyer, CHRC
Nancy Lawand, Secretariat for Disabled Persons